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# Sexualtiy [Sexuality] Resource for Caregivers of Adolescents with Down Syndrome

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SEXUALTIY RESOURCE FOR CAREGIVERS OF ADOLESCENTS  
WITH DOWN SYNDROME

By

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This Scholarly Project Paper, submitted by Katie Carlson & Karna Plaine, in partial fulfillment of the requirement of the Degree of Master's of Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.

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## PERMISSION

Title                      Sexuality Resource for Caregivers of Adolescents with Down Syndrome

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## ABSTRACT

The purpose of the scholarly project was to develop a comprehensive sexuality communication tool for developmentally delayed individuals, facilitating problem identification, mutual goal setting, and development of a consistent approach to sexuality intervention across the home and school contexts. The Youth Sexuality Index (YSI) was developed following a thorough literature review of sexuality, sex education, developmental delays, and Down syndrome-related topics. Following the review of literature, the need was identified for a sexuality communication tool for individuals with developmental and cognitive delays. Healthy sexuality is necessary for one to develop self-esteem and experience meaningful relationships. However, lack of communication and mutual understanding may lead to misperceptions regarding a developmentally delayed child's sexuality (Murphy & Elias, 2006). Likewise, open and detailed discussion about sexuality may be hindered by discomfort by parents and children (American Academy of Pediatrics, 2006).

The Youth Sexuality Index (YSI) product seeks to address this problem. The product is based on the Model of Human Occupation (Kielhofner, 2008) and the underlying assumptions of the Mediated Learning Experience (MLE) Theory (Katz, 2005). The YSI incorporates parent, child, and educator information into sexuality goal setting for children with developmental and cognitive delays. Each section of the YSI serves to provide necessary information to develop a comprehensive foundation on which to base the sexuality education process.

## CHAPTER I

### INTRODUCTION

Healthy sexuality is necessary for one to develop self-esteem and autonomy, as well as experience fulfilling and meaningful relationships. However, lack of communication and mutual understanding may lead to misperceptions regarding a developmentally delayed child's sexuality. Despite the physical capabilities of individuals with Down syndrome to engage in sexual activities, many individuals with disabilities are viewed as childlike, innocent, and asexual beings (Murphy & Elias, 2006). However, persons with intellectual and developmental disabilities have the same sexual desires and dreams as normally developing peers (Ailey et al., 2003). This product focuses on the need for a resource to promote healthy sexual expression for the developmentally delayed and cognitively impaired population in the adolescent age group.

Individuals with intellectual or developmental disabilities may experience incest, abuse by caregivers or persons of authority, and abuse from others with cognitive impairment (Ailey et al., 2003). Fear of abuse and sexual acting out may limit caregivers from addressing sexuality openly with their child. Unfortunately, children with disabilities typically have fewer opportunities for socialization and engagement with others due to parents' fear regarding their child's vulnerability (Murphy & Elias, 2006; Suris et al., 1996). The lack of socialization limits the adolescent's opportunity to participate in normal sexual experimentation, restricting the development of healthy

sexuality and social relations. Individuals with disabilities are often perceived as one extreme or the other, being asexual or sexual deviants.

Communication is the key to understanding a child's sexuality. Unfortunately, more than 70% of parents do not feel comfortable talking to their child with Down syndrome about sexual matters (Peuschel & Schola, 1988), which may be due to difficulty determining which topics to address and the level of detail to use in relation to their child's cognitive ability. Parents may misperceive the sexual knowledge their child currently possesses and may view their child as asexual without interest in intimate relationships. This misperception may be cause false conclusions to be drawn leading to negative consequences for both the parent and child. Family values need to be considered throughout the educational process. However, parents may lack a basic understanding of their child's values and interests regarding sexuality, as well as a strong foundation of their values and beliefs on which to base the education they provide.

A comprehensive sexuality communication tool for developmentally delayed adolescents is necessary to address these problem areas. The Youth Sexuality Index (YSI) facilitates problem identification, mutual goal setting, and development of a consistent approach to sexuality intervention across the home and school contexts. The YSI incorporates parent, child and educator information into sexuality goal setting for children with developmental and cognitive delays. Each section of the YSI serves to provide necessary information to develop a comprehensive foundation on which to base the sexuality education process. By gathering input from multiple participants and facilitating communication on sexuality issues, the topic of sexuality can be properly

addressed. This may result in the development of healthy sexuality among the adolescent with developmental delays, leading to increased overall life and relationship satisfaction.

The YSI application is dependent on a multitude of factors. Identified factors include the following: perceived role of occupational therapy in regards to sexuality; the individual therapist's level of comfort with sexuality topics; the child's level of cognitive abilities; participant investment in YSI process and overall motivation; participant family dynamics; social acceptance of the YSI within specific contexts; and product funding and reimbursement of the YSI process.

The YSI is based on the Model of Human Occupation (MOHO) and its components. In the MOHO, humans are conceptualized as being made up of three interrelated components: Volition, Habituation, and Performance Capacity (Kielhofner, 2008). The MOHO is not designed for a specific type of impairment, but rather is applicable to any person experiencing problems in occupational life and across the lifespan.

The YSI addresses volition through the Caregiver Defining Values Worksheet. The worksheet assists caregivers in determining what he or she feels is meaningful for their child's sexuality and their sense of competence in addressing the areas of sexuality through education. The YSI addresses the child's volition through the CSP portion of the communication tool by acknowledging what sexuality areas are prioritized by the child and their relationship desires and needs. The MOHO concept of habituation is addressed by considering the family's habits, each caregiver's educational role, and the child's perceived roles of his or her own sexuality. A child's habits and routines in the academic setting are also considered as the teacher completes and shares the School-based

Sexuality Checklist. The Caregiver Defining Values Worksheet analyses the caregiver's comfort level and perceived competence in addressing his or her child's sexuality. The child's performance capacity is analyzed by considering the child's sexuality performance from the caregivers', the teacher's, and the child's perception. The child's current sexual knowledge and cognitive abilities are addressed during the CSP sub-test. Both the home and academic environments are incorporated into the YSI assessment as an individual's occupational performance regarding sexuality may vary according to contextual factors.

The underlying assumptions of the Mediated Learning Experience (MLE) Theory were also considered in the development of the YSI. In the MLE a child's perception of the world and processing of information is facilitated by a mediator, such as a parent or caregiver. The MLE proposes that there are certain functions a child can master only through the mediation by an adult or a competent peer. The MLE Theory is based on the assumption that the major factor causing cognitive differences among people is the presence of a mediator, indicating that an involved, knowledgeable parent can promote greater functioning in individuals with intellectual and developmental disabilities (Katz, 2005). Both the parent and educator may serve as filters of the information a child is exposed to and how the information is processed. Therefore, both parents and educators need to have a uniform approach to the child's sex education, a task only feasible with adequate communication and mutual understanding and goal setting.

The more often and the earlier the individual is subjected to mediation the better the outcome. Likewise, the less mediation the developing individual is offered, the lower his or her capacity will be affected by direct exposure to environmental stimuli. The CSP

is aimed at children as young as eight years old, initiating the mediation process prior to pubertal onset. The mediator or parent, guided by his or her intentions, culture, and personal values, selects and organizes the world the child is exposed to and how he or she interprets the stimuli presented (Katz, 2005). The personal values of both the caregiver(s) and the child are represented in the Defining Values Worksheet and Values Rating Scale, with the ultimate objective being facilitation of communication and understanding.

Through mediation, the child's cognitive functions and behavior patterns are affected, indicating the ability of parents to promote or inhibit a child's sexuality. Mutual understanding between all participants prior to the initiation of the mediation process is essential. Understanding is not feasible without communication, which is why the YSI can play a vital role in the sexuality education of developmentally delayed individuals.

The subsequent chapters provide an overview of the background research and product development. An extensive literature review guides the development of the YSI product. Chapter II includes a review of literature providing an overview of the identified problem and current research on the topic of Down syndrome, sexuality and sex education. Chapter III describes how the literature informed the product. A detailed description of the process used in designing the YSI is included. The guiding models are identified and the application process is described in this section. A complete example of the YSI product is provided in Chapter IV for reader viewing. The project summary is in Chapter V which consists of the project purpose and brief overview, limitations of the project, proposals for how the project could be implemented, and future recommendations for product application and improvement. A complete list of project and product references is provided at the end of the scholarly project.

## CHAPTER II

### REVIEW OF LITERATURE

Down syndrome is a genetic condition characterized by delays in physical and intellectual development and is the most frequently occurring chromosomal disorder to date, affecting approximately 1 in every 800 live births (National Association of Down syndrome, 2008). It is estimated that in the United States 6,000 infants are born each year with Down syndrome (Mayo Clinic, 2007). Despite the widespread use of prenatal screens, the prevalence of Down syndrome continues to be on the rise (Riper, 2007); additionally, with improvements in medicine and technology it is anticipated that the number of children and adolescents with Down syndrome could also increase in the next few years. Increasing prevalence may be due to a number of factors, one being the increased number of woman 35 years of age and older continuing to have children (Besser et al., 2007). It has been known for some time that the incidence of Down syndrome increases with advancing maternal age. However, 80% of children with Down syndrome are born to women under 35 years of age. Down syndrome is not related to race, nationality, religion or socioeconomic status (National Association of Down syndrome, 2008). Each person is equally susceptible to being directly or indirectly impacted by this condition.

Individuals with Down syndrome are susceptible to a number of health concerns beyond the normal illnesses associated with childhood. Approximately 40% of children



with Down syndrome have congenital heart defects. Likewise, they are more susceptible to infections, respiratory, hearing, vision and thyroid complications (National Association of Down syndrome, 2008). High rates of obesity are common among individuals with Down syndrome compared to the typically developing population, leading to a multitude of other health related concerns (Jobling & Cuskelly, 2006). Despite the increased rate of morbidity and mortality among the Down syndrome population most children and adults with Down syndrome can lead healthy lives due to advancements of medical technology and receiving appropriate medical care. The average life expectancy of individuals with Down syndrome is 55 years, with many living into their 60s and 70s (National Association of Down syndrome, 2008).

Although Down syndrome can not be prevented, there are factors that place parents at an increased risk for conceiving a child with Down syndrome. Advancing maternal age, past offspring diagnosed with Down syndrome, and carrying the genetic translocation for Down syndrome are all factors that can increase an individual's risk of having an infant with Down syndrome (Mayo Clinic, 2007). Although the underlying cause of developing Down syndrome is unknown, the cellular process leading to this genetic abnormality is well researched.

The origin of Down syndrome can be traced to an abnormality involving the 21<sup>st</sup> chromosome which is responsible for the physical features and developmental problems associated with Down syndrome. It is these physical characteristics – flattened facial features, protruding tongue, small head size, upward slanting eyes, poor muscle tone, and short fingers with a single palmer crease – that typically identify the presence of Down syndrome at birth. The chromosomal abnormality may present itself in one of three

variations, each resulting in extra genetic material leading to 47 chromosomes instead of the usual 46. A diagnosis of Down syndrome must be confirmed by a chromosome study or karyotype to ensure accuracy (National Association for Down syndrome, 2008; Mayo Clinic, 2007).

The key developmental areas that are affected in a child with Down syndrome are the cognitive components of thinking, reasoning and understanding. In fact, Down syndrome is the most common cause of genetically based mental retardation. While cognitive impairments are often apparent, the social and emotional development among individuals with Down syndrome may appear more intact due to typical Down syndrome personality traits (Ghosh et al., 2008). Across numerous studies it has been found that children with Down syndrome present etiology-related personalities, being reported by mothers as loving, out-going, happy, affectionate, and friendly (Hodapp et al., 2003). Individuals with Down syndrome have been associated with having baby-faced features in general, including being more immature, naïve, honest, cuddly, and complaint (Dykens et al., 2002). It is these compounding factors of delayed cognitive abilities and problematic social skills, dependence on others for intimate cares, increased exposure to a number of caregivers, and lack of strategies to defend themselves, that make the Down syndrome population more susceptible to exploitation and abuse (Murphy & Elias, 2006; Ailey et al., 2003).

Individuals with intellectual or developmental disabilities may experience incest, abuse by caregivers or persons of authority, and abuse from others with cognitive impairment (Ailey et al., 2003). Reiter, Bryen and Shachar (2007) found that students 12 to 21 years of age with intellectual and other disabilities experienced physical, sexual and

emotional abuse at significantly higher rates than normally developing peers. Approximately 36 of every 1,000 children with disabilities are maltreated, indicating a rate 1.7 times higher than that of children without physical or cognitive impairments (American Academy of Pediatrics, 1996). In addition, 79% of women in the United States with intellectual and developmental disabilities are more likely to be sexually abused. Sexual abuse among intellectually impaired individuals in the United Kingdom has been reported at 61% for females and 25% for males. Sexual mistreatment among disabled peers is also problematic. Women and young girls with intellectual or developmental disabilities living in residential institutions are likely to experience sexual violence within their setting (Ailey et al., 2003). Not only is the incidence of abuse higher among intellectually impaired children, the abuse often goes unreported and the emotional, psychological and social effect is as debilitating, if not greater, than those without disabilities. In contrast to normally developing peers who report abuse to peers, children with disabilities most often report directly to families (66%) and professionals (33.3%) (Reiter, Bryen & Shachar, 2007). The ability of developmentally delayed individuals to consent to sexual relationships is debated. Capacity to consent requires both a basic knowledge and some comprehension of the right to say 'No,' as well as understanding of the risk of ill-treatment (Murphy & O'Callaghan, 2004). Law enforcement officers, licensing personnel, and sex counselors, often do not use legally relevant criteria when assessing the sexual abuse of individuals with disabilities (Ailey et al., 2003). When sexual offenders of disabled individuals are prosecuted and convicted, they often receive a lighter sentence than those who committed similar crimes to non-disabled persons (Reiter, Bryen, & Schachar, 2007).

Fear of abuse is one of many areas of stress for parents of children with Down syndrome. Because of the unique health, developmental, and educational concerns commonly associated with Down syndrome, parents face a multitude of challenges and generally experience higher levels of stress than families of typically developing children (Riper, 2007). Individuals with Down syndrome often present a multitude of behaviors that may impact their ability to function in both home and school settings. Mothers of children with Down syndrome report significant behavior problems including teeth grinding, self-injury, stereotypy, sleep disorders, feeding disorders, preservation, and excessive speech. Conduct disorder, social withdrawal, attention problems, as well as psychotic behaviors, were of greatest concern to teachers of children with Down syndrome (Coe et al., 1999). Child and parent-related stress complicate the incidence of maladaptive behaviors (Hadopp et al., 2003). Mothers of children with Down syndrome reported less stress and maladaptive behaviors than other same-aged children with developmental disabilities; however, they lack the adaptive behavior skills to cope with both positive and negative life events (Coe et al., 1999). Parents and teachers of children with Down syndrome are often challenged due to the children's presentation of disruptive and inappropriate behaviors, as well as their increased difficulty managing stressful situations.

The disruptive behaviors in the home and classroom may be due to a dual diagnosis of psychiatric and/or behavioral disorders. Individuals with Down syndrome are at risk for behavioral, emotional, and psychiatric problems leading to disruptive behaviors in the home and classroom. Approximately 40% of intellectually disabled individuals have clinically significant behavioral or emotional concerns (Dykens, 2007).

Children with intellectual disabilities are at twice the risk of having problems with inattention, impulsivity, and disturbed thinking or mood than their normally developed peers. Specifically, 6% to 8% of children with Down syndrome are diagnosed with Attention Deficit Hyperactivity Disorder and approximately 15% of children or young adults are diagnosed with conduct or oppositional disorders, indicated by noncompliant, disobedient, or aggressive behaviors (Dykens, 2007; Coe et al., 1999).

The presentation of maladaptive behaviors among the Down syndrome population typically shifts as a child progresses into adolescent years. Compared to typically developing controls, 4 to 8-year-old children with Down syndrome are more likely to exhibit externalizing behaviors such as stubbornness, opposition, inattention, speech problems, poor concentration, attention-seeking, and impulsivity. Children with Down syndrome in this younger age group scored significantly higher on hyperactivity assessments than older adolescent participants. As individuals with Down syndrome progress into adolescence, there is a decrease in externalizing behaviors. Internalizing behaviors, such as social withdrawal, somatic complaints, and acting anxious, become more prevalent during adolescence. Adolescents with Down syndrome were described as preferring to be alone, secretive, and not wanting to talk to others (Dykens et al., 2002). The impact of internalizing behaviors on depression can directly influence the child-parent relationship. Compared with their younger peers, Hodapp et al. (2003) found that adolescents with Down syndrome apt to be rated by parents as less fun, outgoing, humorous, cheerful, or affectionate. Parents of children with Down syndrome reported feeling a high sense of reward from their children, which may be due to the pleasant behaviors eliciting specific emotional reactions from their parents. Parental satisfaction

has been found to significantly decline over the adolescent years, when the typical pleasant Down syndrome behaviors decrease. The child's age is a strong predictor of parental satisfaction, with mothers considering their older children less rewarding (Hodapp et al., 2003). The increased stress associated with having adolescents with Down syndrome can further complicate the transitional period of puberty.

Adolescence is often a challenging time during a teen's life for both the child and the family unit. While this may be a troublesome period for those with normal intellectual abilities, a cognitively impaired individual's problems are often amplified. Young people with intellectual disabilities, including Down syndrome, often have normal physical attributes but do not possess the mental capabilities to cope with the transition effectively (Pueschel & Scola, 1988). Comprehending and coping with physical and emotional changes can challenge individuals with disabilities. At this time there is an increase in the hygiene demands for adolescence and many times young people with Down syndrome lack awareness of their ability to independently perform hygiene tasks. Parents frequently need to remind their adolescent of appropriate behaviors to ensure regularity and thoroughness of hygiene tasks (Jobling & Cuskelly, 2006). Hygiene among this population needs to be addressed as adolescents with Down syndrome experience the same sequence of physical and hormonal changes associated with puberty as other children their age (National Down Syndrome Society, 2008).

Secondary sex characteristics develop in females with Down syndrome in the same cycle as typically developing peers. Scola and Peuschel (1992) found that the average onset for menstruation is 12 years, 6 months, and almost all of the women with Down syndrome in their study had normal ovulation and menstrual cycles. Although

puberty in males may be slightly delayed; genital anatomy is comparable to that of boys who do not have Down syndrome (National Down syndrome Society, 2008). The major difference among Down syndrome males compared to normal developing peers is a decreased sperm count and ejaculation rate, leading to a decrease in fertility rates among Down syndrome males (Van Cleve, Cannon, & Cohen, 2006). It must be noted that both males and females with Down syndrome are anatomically capable of producing offspring.

Despite the physical capabilities of individuals with Down syndrome to engage in sexual activities, many individuals with disabilities are viewed as childlike, innocent, and asexual beings. Attention is given to complex medical and functional issues rather than physiological, emotional, and social components of developing sexuality (Murphy & Elias, 2006). In the past, sexuality was not considered an issue for young people with Down syndrome due to the inaccurate belief that mental retardation was equivalent to permanent childhood (National Down syndrome Society, 2008). Western societies have traditionally associated sex with procreation assuming sexuality is reserved for those with good health (Suris et al., 1996). Social stigma negatively impacts the sexual expression of individuals with disabilities. Historically, sterilization of minors with developmental disabilities was completed without consideration of the individual's rights, decision-making capacity, ability to parent, feelings or desire to express sexuality. Societal and psychological barriers may have a greater negative impact on an adolescent's sexual maturity than the limitations of the disability itself (Murphy & Elias, 2006).

Sexual behavior is socially learned, shaped, and reinforced within many social contexts including family, community, school, and friends (Suris et al., 1996). Like normal developing peers, experimentation is a key component of social development

among children with disabilities. Unfortunately, children with disabilities typically have fewer opportunities for socialization and engagement with others due to parents' fear regarding their child's vulnerability (Murphy & Elias, 2006; Suris et al., 1996). The lack of socialization limits the adolescent's opportunity to participate in normal sexual experimentation, restricting the development of healthy sexuality and social relations. Individuals with disabilities are often perceived as one extreme or the other, being asexual or sexual deviants. What may be assumed as normal sexual behaviors among non-disabled adolescents may be deemed inappropriate or bad among individuals with disabilities (Ailey et al., 2003).

Parents and society look upon individuals with Down syndrome as dependent, incapable of making decisions and developing autonomy (Pueschel & Schola, 1988). While the emphasis on mainstreaming individuals with disabilities into the same context as able-bodied peers has grown, sexuality and sexual expression continue to be controversial. Individuals with intellectual and developmental disabilities often have little contact with other individuals with whom they could expect to form intimate relationships despite having opportunities to develop social networks in educational and residential settings (Ailey et al., 2003). Shepperson (1995) reports that individuals with Down syndrome are not left alone at home for more than 15 minutes at a time and many are unable to go into the community without high levels of supervision. Activities for adults and teens at clubs, schools, and centers are strictly supervised, and attendance would likely decline if supervisors were not present (Shepperson, 1995). Likewise, children and adolescents in segregated settings typically have little or no opportunities to visit friends outside of the residential environment, often being denied to see friends or



‘boyfriends-girlfriends’ in other locations. Developmentally delayed adolescents living at home are often limited to their parents’ social networks, and unfortunately, this trend continues among adults with disabilities as well (Ailey et al., 2003).

In addition to the social isolation imposed on individuals with developmental delays, parents and society have misperceptions regarding the desire for intimacy and marriage among this population. Puschel and Scola (1988) researched parents’ perceptions of the social and sexual functioning of their adolescents with Down syndrome. Parents reported their children as social, enjoying dancing and meeting new people; however, parents were unsure about their child’s future regarding intimacy, marriage, and sexual relationships. Some parents were apprehensive regarding marriage, expressing concerns that their child may not understand the responsibilities and consequences associated with this type of commitment. Shepperdson (1995) found that parents’ perceptions of marriage were dependent on what was perceived as the main aim of marriage. If ‘caring’ or ‘being close’ was emphasized, marriage was viewed as appropriate or desired. In comparison, if the responsibilities within a marriage, such as domestic tasks or parenting, were emphasized, parents doubted the suitability of their children. In regards to relationships, parents reported feeling that others in the community would react negatively if their youngsters would become sexually active and felt their child should not be exposed to sexual relationships as they could not cope appropriately (Pueschel & Scola, 1988).

All individuals, regardless of disability, are sexual beings and have the right to express sexuality as they wish. Society may place prejudice upon individuals with Down syndrome and other intellectual disabilities who engage in sexual behavior; therefore, it is

difficult for these individuals to become secure in their own sexual identity. Current research regarding the level of sexual activity among the Down syndrome population is limited. One of the most common methods of sexual expression regardless of abilities is masturbation, the rhythmic self-stimulation of one's own genital area. In some severely cognitively impaired individuals, masturbation may appear as a form of self-injurious behavior leading to direct negative responses by parents and other authority figures. By receiving negative feedback for masturbating, individuals with disabilities are conditioned to think this activity is wrong (Ailey et al., 2003; National Association for Down Syndrome, 2008). Masturbation among individuals with Down syndrome has been reported at rates of 40% in males and 52% in females (Pueschel, 1986). In a study on parents' perceptions of the social and sexual functioning of their adolescents with Down syndrome, 64% of parents stated their sons had erections with only 28% having noticed ejaculation. It was found that 40% of male and 22% of female participants had been observed masturbating by their parents. Participants reported understanding this sexual expression of their child but regardless were embarrassed when it occurred in public (Pueschel & Scola, 1988). Despite the stigmas of sexuality among disabled people, rates of masturbation among individuals with Down syndrome are not significantly higher than those in the general population (as cited in Van Dyke et al., 1995).

Persons with intellectual and developmental disabilities have the same sexual desires and dreams as normally developing peers (Ailey et al., 2003). Suris et al. (1996) compares the sexual behavior among adolescents with and without chronic conditions and suggests that adolescents with chronic conditions are at least as sexually active as their healthy peers. The mean age of first intercourse for males is approximately 13 years

old. There is no significant difference among females with disabilities and those without in regards to ever having sex. The age at first intercourse for females ranges from 13.9 to 14.2 years old. Likewise, no group differences were found in pregnancy history.

However, the study found that those with chronic conditions experienced more negative consequences of their sexual behavior than their able-bodied peers. Those with visible conditions were significantly more likely than controls to report ever having a sexually transmitted disease (STD) (Suris et al., 1996). People with intellectual or developmental disabilities, compared to peers with physical disabilities, typically experience lower levels of sexual knowledge and experience, more negative attitudes towards sex, and more prevailing sexual needs in all areas of sexuality (Ailey et al., 2003).

Interest in sexual expression is present in adolescents regardless of diagnosis. Pueschel and Schola (1988) report that over half of the young people with Down syndrome show interest in the opposite sex, and the source of interest was found to vary depending on gender. Males are more comfortable with and show interest in pursuing discussions of male-female relationships (Rothenberg, Franzblau, & Geer, 1979), where females show greater interest in getting married and discussing sexual exploitation and the ability of disabled individuals to bear children and parent (Rothenberg, Franzblau, & Geer, 1979; Pueschel & Scola, 1988).

Providing intellectually disabled children and adolescents with quality sexuality education has many benefits that go beyond a basic understanding of sexuality topics. Not only will individuals be able to protect themselves from the negative effects of exploitation, unplanned pregnancy, and STDs, adolescents also gain a greater sense of self-confidence by realizing that peers with disabilities are experiencing the same

changes and social stigmas. Adolescents can develop skills for recognizing and responding to social situations appropriately. Communication skills may be improved as a greater understanding is gained. Articulating goals and recognizing potential for realistic future relations becomes possible resulting in empowerment and self-concept (Mauer, 2007). Education can prepare children for protecting their own body and in reporting violations to trusted adults (American Academy of Pediatrics, 1996). Some parents fear that discussing sexuality with their children will promote sexual behaviors, but lack of education poses greater risk (Murphy & Elias, 2006). An individual's inability to develop healthy sexuality through knowledge and understanding may cause mental disorders such as anxiety, depression, and adjustment disorders, as well as impaired self-esteem (Ailey et al., 2003).

Comprehensive sex education needs to extend beyond the traditional areas of anatomy, intercourse, and physiologic functions. Sexuality should be taught to facilitate self-esteem and autonomy. Sex education in its broadest sense will provide children a sense of being attractive members of society with expectations of having healthy, satisfying adult relationships (American Academy of Pediatrics, 1996; Murphy & Elias, 2006). Sexuality is a key component of how individuals see themselves and the world around them. The ability to acknowledge the interconnection between themselves and others in the world is a big part of what makes individuals humans. People with disabilities should not miss the opportunity to experience fullness in their relationships and the pleasures they can enjoy (King, 2007).

Providing sexual education raises controversy for typically developing children and has additional complexities when considered for children with disabilities (American

Academy of Pediatrics, 1996). Sexuality is theoretically a basic human right, granted to all individuals despite ability. However, the development of sexuality is dependent on the knowledge and opportunities to make decisions to control one's life and build relationships with others. Although the general population receives their sex education from numerous resources, including parents and friends, intellectually and developmentally disabled individuals are more likely to receive information strictly from formal education programs and the media (Ailey et al., 2003). Sexuality resources for disabled individuals may be difficult to locate and apply, and the educational materials that are provided are targeted for children without disabilities and not helpful for those with cognitive delays (American Academy of Pediatrics, 1996).

Children with Down syndrome can not learn about sexuality sufficiently from friends, peers, books or observing others. This leaves parents to address their child's deficit in sexuality knowledge. Pediatricians and educators encourage parents to be the principle teachers of developmentally appropriate sexuality education for their children, incorporating family values, cultural traditions, and religious beliefs (Murphy & Elias, 2006). Unfortunately, more than 70% of parents do not feel comfortable talking to their child with Down syndrome about sexual matters (Peuschel & Schola, 1988), which may be due to difficulty determining which topics to address and the level of detail to use in relation to their child's cognitive ability. Sexuality resources for disabled individuals are difficult to locate and apply, and the educational materials that are provided are targeted for children without disabilities and not helpful for those with cognitive delays (American Academy of Pediatrics, 1996).

Having parents serve as their child's primary sex educator is supported by the Mediated Learning Experience (MLE) Model in which a child's perception of the world and processing of information is facilitated by a mediator, such as a parent or caregiver. The MLE possess that there are certain functions a child can master only through the mediation by an adult or a competent peer. The MLE Model is based on the assumption that the major factor causing cognitive differences among people is the presence of a mediator, indicating that an involved, knowledgeable parent can promote greater functioning in individuals with intellectual and developmental disabilities. In fact, the more often and the earlier the individual is subjected to mediation the better the outcomes. Likewise, the less mediation the developing individual is offered, the lower his or her capacity will be affected by direct exposure to environmental stimuli. The mediator or parent, guided by his or her intentions, culture, and personal values, selects and organizes the world the child is exposed to and how he or she interprets the stimuli presented (Hadas-Lindor & Weiss, 2005). Through this filtering the child's cognitive functions and behavior patterns are affected, indicating the ability of parents to promote or inhibit a child's experiences including those related to sexuality.

Parents and care-providers are perceived as understanding their child's needs and knowing their level of sexual activity, imposing an incredible burden when parents may not know how to use this knowledge for their child's best interest (Shepperdson, 1995). Although parents are assumed to know most about their child, sexuality is one area that may be misjudged. Parents may misperceive the sexual knowledge their child currently possesses and may view their child as asexual without interest in intimate relationships. This misperception may be cause false conclusions to be drawn leading to negative

consequences for both the parent and child. Family values need to be considered throughout the educational process. However, parents may lack a basic understanding of their child's values and interests regarding sexuality, as well as a strong foundation of their values and beliefs on which to base the education they provide.

Support systems and guidance for parents are needed to ensure appropriate opportunities for meaningful sexual and personal relationships among their children with developmental disabilities (Parker & Abramson, 1995; Shepperdson, 1995). Resources are available to assist in choosing the most effective words or methods to use to explain sexuality to children with Down syndrome; however, without a baseline understanding of the child's current knowledge a parent or caregiver may not know where to begin the educational process. Sexuality resources need to be readily available and user-friendly for parents to reference while teaching developmentally appropriate sexuality education.

A resource to aid parents in gaining a greater understanding of their own and their child's sexual values is necessary in order to solidify the approach taken to the educational process. Defining parental and child values promotes greater insight and intuition into the family dynamics and culture in which the education occurs. An assessment of a child's current sexuality knowledge is also necessary. If a parent is able to grasp a basic understanding of their child's current knowledge in the areas of anatomy, personal hygiene, pubertal changes, personal boundaries and sexual expression, they will be better prepared to communicate and educate their child on intimate issues and encourage the development of the adolescent's sexual identity. A primary educator may also have valuable input into a child's sexual knowledge by noting vocabulary and behaviors present in the academic setting. Gaining a baseline of sexual knowledge in

combination with defining child and family values will assist caregivers in effectively communicating with healthcare professionals and educators regarding sexual issues. A user-friendly sexuality resource and communication tool for parents of children with developmental delays will assist in effectively determining a child's current sexual knowledge as well as defining both the parents' and child's values regarding sexuality. A Caregiver Defining Values Worksheet, Child Sexuality Profile (CSP) assessment tool, School-based Sexuality Checklist, and supplemental sexuality resources and education guidelines will assist parents in the challenging, yet rewarding endeavor of addressing sexuality with their child.



## CHAPTER III

### METHODOLOGY

#### Product Introduction

The Youth Sexuality Index (YSI) is a comprehensive sexuality communication tool that facilitates problem identification, mutual goal setting, and development of a consistent approach to sexuality intervention across the home and school contexts. The YSI incorporates parent, child and educator information into sexuality goal setting for children with developmental and cognitive delays. The YSI tool consists of three main sub-tests: Caregiver Defining Values Worksheet, Child Sexuality Profile (CSP), School-based Sexuality Checklist, followed by Integration. Each sub-test serves to provide necessary information to develop a comprehensive foundation on which to base the sexuality education process.

#### Data Gathering

The YSI product was developed following a thorough literature review of sexuality, sex education, and Down syndrome related topics. References were gathered using the PubMed database, Academic Search Premiere, CINAHL, MEDLINEplus, and other resources from the Harley E. French Library of Health Sciences. Various organizational websites were reviewed for supplement educational materials. Some of the organization websites reviewed include the following: the American Academy of Pediatrics, the Sexuality Information and Education Council of the United States, the Arc:

National Organization on Mental Retardation, and the American Association on Mental Retardation. Each author compiled various references and shared information with each other. Articles were cross-referenced for consistency in data and emerging themes. Following the review of literature, the need was identified for a sexuality communication tool for individuals with developmental and cognitive delays.

### Product Development

According to the American Academy of Pediatrics (2006) the five areas of sexuality that need to be integrated into sexuality education for developmentally delayed individuals are: anatomy, hygiene, pubertal changes, personal boundaries and sexual expression. Each section of the YSI focuses on these sexuality areas, allowing cross-comparison of each sub-test on specific topics by the occupational therapist.

The purpose of the Defining Values Worksheet is to assist caregivers in determining individual and mutual values regarding their child's sexuality. Parents are to incorporate family values, cultural traditions, and religious beliefs into sex education (Murphy & Elias, 2006), indicating the need for caregivers to solidify their own values and beliefs before teaching their child about sexuality. The Defining Values Worksheet aids caregivers in determining the importance of addressing sexuality with their child and considering their goals and dreams for the child's future. Pediatricians and educators encourage parents to be the principle teachers of developmentally appropriate sexuality (Murphy & Elias, 2006); however, more than 70% of parents do not feel comfortable talking to their child with Down syndrome about sexual matters (Peuschel & Schola, 1988). A communication tool is therefore necessary to facilitate open and honest

communication regarding sexuality between the caregiver(s) and child to initiate and continue the educational process.

The Child Sexuality Profile (CSP) is a client centered assessment tool designed to determine a child's current sexuality knowledge and his or her values and perceived competency in sexuality. The CSP assists the therapist in learning what type of sexuality goals the child wants and what is most important to him or her. The CSP consists of a Competency Rating Scale and a Values Rating Scale, each including a series of statements pertaining to everyday sexuality occupations. Knowledge flashcards are included to determine the child's current knowledge in each area of sexuality and to prompt additional conversation on sexuality topics.

The Child Occupational Self Assessment (COSA) was utilized in the development of the CSP. The formatting and administration methods of the COSA served as a guide for the development of the CSP Values and Competency Rating Scales. The COSA was chosen because its target population is children between the ages of eight to thirteen years, which is the same age group the CSP targets. This age group was chosen because sexuality education needs to begin at a younger age, addressing the physical and emotional changes that occur during puberty prior to onset. In addition, the administration of the card sort task was applicable to the CSP purpose by allowing the child to express his or her responses in an interactive manner.

Because the CSP is intended for use by developmentally and cognitively delayed individuals modifications to the COSA were necessary. When working with individuals with developmental delays, specifically those with Down syndrome, it is recommended that the educator use simple words and visual aids to assist in teaching. The sexuality

teaching process should be consistent across all contexts and be as concrete as possible (Murphy & Elias, 2006). Moreover, the developmentally delayed population benefits from repetition to solidify understanding of concepts (Pueschel, S. M., & Scola, P. S., 1988). Due to the specific educational needs of the developmentally delayed population, the card sort activity was adapted by minimizing the rating scale to three choices, each with simplified vocabulary and universal visual aids. Repetition was integrated into the CSP by overlapping the five areas of sexuality into each section of the CSP – the Values Rating Scale, the Competency Rating Scale, and the Knowledge Flashcards.

The knowledge flashcards section of the CSP was created to determine the child's current knowledge in various areas of sexuality and to prompt additional conversation on sexuality topics. Pictorial illustrations are included on each flashcard to facilitate understanding among lower functioning clients with cognitive delays. The CSP's self-rating design allows the child to determine his or her perception regarding sexual values, personal causation, and performance capacity. The supplemental questions were written in a straight forward and simplistic manner to promote understanding among the participants and allows for additions or alterations by the therapist to meet the individual participant's cognitive ability.

The School-based Sexuality Checklist allows the child's educators to provide input into the child's sexual behaviors in the academic setting. Since an educator typically has experience working with the child in multiple physical and social situations, the School-based Sexuality Checklist provides valuable input into the child's current behavioral patterns and knowledge that may otherwise go undetected. This sub-test aims to determine a student's ability to make choices, fulfill current roles and routines, and

function within the classroom environment. The five sexuality areas included are anatomy, pubertal changes, personal hygiene, personal boundaries, and sexual expression. Comment sections were included under each question that may require additional explanation to prompt understanding by the therapist and other participants. An additional comments section was included to provide the educator with the opportunity to provide information he or she feels is relevant.

Using the information gained through the Caregiver Defining Values Worksheet, Child Sexuality Profile Summary, and School-based Sexuality Checklist, the therapist is to integrate key components from each source to determine primary areas of concern and future sexuality outcomes. Cross referencing of the five sexuality areas of anatomy, hygiene, pubertal changes, personal boundaries and sexual expression will assist the therapist in determining the key areas of concern and goals identified by each participant. The process of developing sexuality goals should be a collaborative process in which the therapist does not dictate the conversation but rather facilitates discussion with each participant until a common conclusion is made. Because parents are to be the primary educators of their child's sexuality, integrating their personal values and beliefs, it is essential that they be involved in the goal setting process. Since the educator and caregiver(s) have the most exposure to the child across multiple contexts and during various social situations, they provide valuable, realistic input into intervention strategies and recommendations. This is especially important because sexual behavior is socially learned, shaped, and reinforced within many social contexts including family, community, school, and friends (Suris et al., 1996). The Integration Worksheet will be used as a communication tool to promote mutual understanding and collaboration towards goals

among all YSI participants, as well as ensure consistency in sexuality education across all contexts. Once goals are set, appropriate sexual behaviors may be consistently reinforced by both caregiver(s) and the primary educator in the child's multiple contexts.

Specific strategies for both the school and home contexts are recommended for each participant. This will allow each participant to recall role specific, child-friendly methods to address each area of concern in the various contexts. A copy of the integration data and additional resources should be provided to each participant to reference when necessary. The Revision Worksheet was created to track changes to the child's sex education program and promote collaboration throughout the entire educational process, rather than just at the beginning. This tool can be used by the therapist to adjust goals and making revisions to the plan as needed.

### Models Guiding Development

The YSI is based on the Model of Human Occupation (MOHO) and its components. In MOHO, humans are conceptualized as being made up of three interrelated components: Volition, Habituation, and Performance Capacity (Kielhofner, 2008). MOHO is not designed for a specific type of impairment, but rather is applicable to any person experiencing problems in occupational life and across the lifespan.

Volition consists of the individual's values (what is important and meaningful), interests (what is enjoyable and satisfying), and personal causation (sense of competence and effectiveness). Volition refers to the motivation for occupation. It is defined as a pattern of thoughts and feelings that predisposes and enables people to anticipate, choose, experience, and interpret behavior. The YSI addresses volition through the Caregiver Defining Values Worksheet. The worksheet assists caregivers in determining what he or

she feels is meaningful for their child's sexuality and their sense of competence in addressing the areas of sexuality through education. The YSI addresses the child's volition through the CSP portion of the communication tool by acknowledging what sexuality areas are prioritized by the child and their relationship desires and needs.

Habituation refers to the processes that maintain a pattern in everyday life. It consists of habits and roles that ensure regularity and predictability to occupational behavior. An individual's roles provide both identity and expectations for behavior. Habits form from repeated behavior within the environment and specific contexts. The YSI addresses habituation by considering the family's habits, each caregiver's educational role, and the child's perceived roles of his or her own sexuality. A child's habits and routines in the academic setting are also considered as the teacher completes and shares the School-based Sexuality Checklist.

Performance capacity is the individual's ability to perform tasks depending on objective and subjective components. Objective components of performance capacity include physical aspects (i.e. musculoskeletal, neurological, cardiopulmonary, and other bodily systems) and psychological aspects (i.e. memory, perception, and cognition). Subjective components incorporate experience as a central factor in how individuals perform. The fundamental assumption of MOHO is that to learn any performance an individual must know how it feels prior to mastery. The Caregiver Defining Values Worksheet analyses the caregiver's comfort level and perceived competence in addressing his or her child's sexuality. The child's performance capacity is analyzed by considering the child's sexuality performance from the caregivers', the teacher's, and the

child's perception. The child's current sexual knowledge and cognitive abilities are addressed during the CSP sub-test.

MOHO recognizes the impact of environment on occupational performance, including both physical and social environments. The physical environment consists of the objects and space that an individual interacts with during occupations. The social environment includes social groups and supports that surround the individual. The physical and social environment can provide supports and resources for participation, or may hinder the individual's performance in meaningful and purposeful tasks. Both the home and academic environments are incorporated into the YSI assessment as an individual's occupational performance regarding sexuality may vary according to contextual factors.

The underlying assumptions of the Mediated Learning Experience (MLE) Theory were also considered in the development of the YSI. In the MLE a child's perception of the world and processing of information is facilitated by a mediator, such as a parent or caregiver. The MLE Theory proposes that there are certain functions a child can master only through the mediation by an adult or a competent peer. The MLE is based on the assumption that the major factor causing cognitive differences among people is the presence of a mediator, indicating that an involved, knowledgeable parent can promote greater functioning in individuals with intellectual and developmental disabilities (Katz, 2005). Because the YSI incorporates data from the home and school context, it is important to consider the multiple mediators that a child may encounter. Both the parent and educator may serve as filters of the information a child is exposed to and how the information is processed. Therefore, both parents and educators need to have a uniform



approach to the child's sex education, a task only feasible with adequate communication and mutual understanding and goal setting.

The more often and the earlier the individual is subjected to mediation the better the outcome. Likewise, the less mediation the developing individual is offered, the lower his or her capacity will be affected by direct exposure to environmental stimuli. The CSP is aimed at children as young as eight years old, initiating the mediation process prior to pubertal onset. The mediator or parent, guided by his or her intentions, culture, and personal values, selects and organizes the world the child is exposed to and how he or she interprets the stimuli presented (Katz, 2005). The personal values of both the caregiver(s) and the child are represented in the Defining Values Worksheet and Values Rating Scale, with the ultimate objective being facilitation of communication and understanding.

Through mediation, the child's cognitive functions and behavior patterns are affected, indicating the ability of parents to promote or inhibit a child's sexuality. Mutual understanding between all participants prior to the initiation of the mediation process is essential. Understanding is not feasible without communication, which is why the YSI can play a vital role in the sexuality education of developmentally delayed individuals.

## CHAPTER IV

### PRODUCT INTRODUCTION

The Youth Sexuality Index (YSI) is a comprehensive sexuality communication tool for developmentally delayed adolescents that facilitates problem identification, mutual goal setting, and development of a consistent approach to sexuality intervention across the home and school contexts. The YSI incorporates parent, child and educator information into sexuality goal setting for children with developmental and cognitive delays. The YSI tool consists of three main sub-tests: Caregiver Defining Values Worksheet, Child Sexuality Profile (CSP), School-based Sexuality Checklist, followed by Integration. Each sub-test serves to provide necessary information to develop a comprehensive foundation on which to base the sexuality education process.

The purpose of the Defining Values Worksheet is to assist caregivers in determining individual and mutual values regarding their child's sexuality. This sub-test aids caregivers in determining the importance of addressing sexuality with their child and considering their goals and dreams for the child's future.

The Child Sexuality Profile (CSP) is a client centered assessment tool designed to determine a child's current sexuality knowledge and his or her values and perceived competency in sexuality. The CSP will assist the therapist in learning what type of sexuality goals the child wants and what is most important to him or her.

The School-based Sexuality Checklist allows the child's educators to provide input into the child's sexual behaviors in the academic setting. The checklist provides valuable input into the child's current behavioral patterns and knowledge that may otherwise go undetected. This sub-test aims to determine a student's ability to make choices, fulfill current roles and routines, and function within the classroom environment.

Using the information gained through the Caregiver Defining Values Worksheet, Child Sexuality Profile Summary, and School-based Sexuality Checklist, the occupational therapist is to integrate key components from each source to determine primary areas of concerns. Cross referencing of the five sexuality areas of anatomy, hygiene, pubertal changes, personal boundaries and sexual expression will assist the therapist in determining the key areas of concern and goals identified by each participant. The process of developing sexuality goals should be a collaborative process. Because parents are to be the primary educators of their child's sexuality, integrating their personal values and beliefs, it is essential that they be involved in the goal setting process. Since the educator and caregiver(s) have the most exposure to the child across multiple contexts and during various social situations, they provide valuable, realistic input into intervention strategies and recommendations.

The Integration Worksheet will be used as a communication tool to promote mutual understanding and collaboration towards goals among all YSI participants, as well as ensure consistency in sexuality education across all contexts. Once goals are set, appropriate sexual behaviors may be consistently reinforced by both caregiver(s) and the primary educator in the child's multiple contexts. Specific strategies for both the school and home contexts are recommended for each participant. This will allow each

participant to recall role specific, child-friendly methods to address each area of concern in the various contexts. The Revision Worksheet was created to track changes to the child's sex education program and promote collaboration throughout the entire educational process, rather than just at the beginning. This tool can be used by the therapist to adjust goals and making revisions to the plan as needed.

The YSI is based on the Model of Human Occupation (MOHO) and its components, as well as the Mediated Learning Experience (MLE) Theory. Both of these guiding models are described in detail within the YSI Overview portion of the product as well as in the methodology described in Chapter III of the project.

Please refer to project Appendix to view complete YSI product.

## CHAPTER V

### SUMMARY

The Youth Sexuality Index (YSI) is a comprehensive sexuality communication tool for developmentally delayed adolescents that facilitates problem identification, mutual goal setting, and development of a consistent approach to sexuality intervention across the home and school contexts. The YSI incorporates parent, child and educator information into sexuality goal setting for children with developmental and cognitive delays. The YSI tool consists of three main sub-tests: Caregiver Defining Values Worksheet, Child Sexuality Profile (CSP), School-based Sexuality Checklist, followed by Integration. Each sub-test serves to provide necessary information to develop a comprehensive foundation on which to base the sexuality education process. Throughout the entire YSI process an occupational therapist mediates each step with collaboration from each participant to promote a client-centered approach to the sexuality education process.

Throughout the development of the YSI it is important to note that the product does present some limitations that must be considered prior to administration. By recognizing potential obstacles to YSI success, one can better prepare to ensure YSI effectiveness and applicability. Because of the comprehensiveness of the YSI, it may be difficult for new audiences to fully understand the scope of the YSI product. The implementation process may become confusing to some people, as multiple participants

and steps are involved. Additionally, the YSI has not been formally tested in the practice setting; therefore, it is impossible to know the true feasibility of the process as a whole. The lack of testing adds additional complexities in determining the applicability of the product with multiple populations. The YSI is developed for children and adolescents ages eight through thirteen years old with developmental delays; however, each individual presents multiple variables, such as amount of insight, cognitive capacity, past experiences, and family dynamics, that may challenge therapists who are determining the appropriateness of the YSI. One individual factor that needs to be considered is cultural background. The rating scale and flashcard visual illustrations may not be appropriate for all ethnic and cultural groups and alternative symbols may be required.

The role of occupational therapy in addressing sexuality may be an area of controversy and debate. Due to the lack of participation that occupational therapists have had in the role of addressing sexuality with this target population, there may be some apprehension and/or hesitation in administering the YSI. Therapists working in an academic setting, such as an elementary or middle school, must focus their intervention on school-based tasks and how his or her impairment impacts the student role. This may limit a therapist's ability to directly consider the impact of sexuality without stepping out of their typical scope of treatment. However, due to the holistic approach to care and focus on meaningful occupations, it would be negligent of the profession of occupational therapy to ignore the role of sexuality.

In order to address the product's limitations, recommendations are provided to improve YSI outcomes and applicability. It is recommended that the YSI be piloted in elementary and middle schools throughout the Greater Grand Forks Area. This would

allow the authors to recognize problem areas, limiting the feasibility and effectiveness of the YSI. Product modifications would be executed based on therapist, educator, and caregiver feedback. Outcomes will be measure using a post-pilot survey focused on product administration feasibility, amount of knowledge gained, application of YSI information in developing integration strategies, and overall satisfaction with results. By obtaining additional information from each piloting therapist regarding the applicability with multiple students with dynamic needs and abilities, added instruction for determining child appropriateness for the YSI could be provided. The YSI sub-tests could be made more objective by providing specific definitions for each card sort item and checklist behavior to limit bias, increase validity, and ensure reliability of the YSI process. Based on the major ethnic groups in the United States, supplementary symbols and photos could be created to meet each individual child and family needs.

The role of occupational therapy in addressing sexuality of child and adolescents with developmental delays needs to be recognized and valued by other healthcare professionals and academic professions. This is only possible through communication with others and education on occupational therapy's scope of practice. The Occupational Therapy Practice Framework may be helpful throughout the educational process. By promoting the profession's role in addressing sexuality, others will become familiar with the valuable role occupational therapy may play in this intimate occupational area.

Additional recommendation on the YSI is necessary to validate the communication process and measure product effectiveness. The authors recommend a qualitative, case study be implemented to gain insight into the communication process and the impact on each participant. The child and caregiver(s) may be interviewed

throughout the process on self-esteem changes noted in the child and levels of life satisfaction in regards to sexuality among both caregivers and children. A pilot study may be implemented in elementary schools throughout the state of North Dakota. Purposive sampling would be used to ensure consistency in child diagnosis and level of development in each participant. Quality of life surveys may be used as a means of measurement. Pre- and Post-intervention behavioral checklists may be completed by caregivers and educators to record any sexual behavior changes. The product may be modified based on research results to increase feasibility of the YSI process.

Although the YSI product presents some limitations, the strengths of the product outweigh the obstacles that may occur. The user-friendly sexuality resource and communication tool will assist in effectively determining a child's current sexual knowledge as well as defining both the parents' and child's values regarding sexuality. Sexual behaviors in both the home and school context will be identified and addressed with client-centered intervention strategies. The sexuality resources and education guidelines included in the Caregiver Sexuality Packet, as well as increased knowledge and awareness, will assist parents in the challenging, yet rewarding endeavor of addressing sexuality with their child.



## APPENDIX

**UND**

University of North Dakota  
Occupational Therapy Department

# Youth Sexuality Index (YSI)

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**2009**

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# YSI Overview

The Youth Sexuality Index (YSI) is a comprehensive sexuality communication tool that facilitates problem identification, mutual goal setting, and development of a consistent approach to sexuality intervention across contexts. The YSI incorporates parent, child and educator information into sexuality goal setting for children with developmental and cognitive delays. The tool consists of three main sub-tests: Caregiver Defining Values Worksheet, Child Sexuality Profile (CSP), School-based Sexuality Checklist, followed by Integration. Each sub-test serves to provide necessary information to develop a comprehensive foundation on which to base the sexuality education process. Each section of the YSI focuses on the sexuality areas of anatomy, personal hygiene, pubertal changes, personal boundaries, and sexual expression.

The purpose of the Defining Values Worksheet is to assist caregivers in determining individual and mutual values regarding their child's sexuality. This sub-test aids caregivers in determining the importance of addressing sexuality with their child and considering their goals and dreams for the child's future.

The Child Sexuality Profile (CSP) is a client centered assessment tool designed to determine a child's current sexuality knowledge and his or her values and perceived competency in sexuality. The CSP will assist the therapist in learning what type of sexuality goals the child wants and what is most important to him or her.

The School-based Sexuality Checklist allows the child's educators to provide input into the child's sexual behaviors in the academic setting. The checklist provides valuable input into the child's current behavioral patterns and knowledge that may otherwise go undetected. This sub-test aims to determine a student's ability to make choices, fulfill current roles and routines, and function within the classroom environment.

This manual is designed to provide the therapist with the necessary guidelines and forms for using the YSI communication tool in practice. Therapists are encouraged to thoroughly study all materials prior to administering the YSI and to follow the provided guidelines.

Although not all sub-tests are required for administration of the YSI, it is recommended that the therapist gather as much information as needed to determine the most appropriate approach to sex education. The educator and parents may complete the Defining Values Worksheet and School-based Sexuality Checklist independently with prior instruction; however, the therapist must administer the CSP portion of the YSI according to the included instructions.

## Purpose

The YSI was designed for parents and their children with developmental delays who are seeking to start the sexuality education process. It is appropriate for a wide range of children and adolescents with varying cognitive abilities. However, the appropriateness of the YSI should be determined on an individual basis based on the therapist's clinical judgment and experience working with the child. Attention span, fine motor abilities, insight, and ability to think abstractly are relevant characteristics to consider prior to administering the YSI. This assessment is made specifically for developmentally delayed individuals but not one specific diagnosis. The therapist should be familiar with the client and may determine appropriateness in collaboration with the primary caregivers.

The YSI is most appropriate for clients who:

- Are between the chronological ages of 8-13 years
- Have moderate ability to self-reflect and express self
- Have adequate ability to follow simple commands and answer questions
- Have moderate verbal skills, although not necessary
- Have parents who are willing to collaborate on the goal-setting process

The YSI is not appropriate for clients who:

- Have severe cognitive limitations
- Have minimal insight into strengths/weaknesses and personal goals
- Have visual impairments

## *Part II: Caregiver Defining Values Worksheet*

The purpose of the Defining Values Worksheet is to assist caregivers in determining individual and mutual values regarding their child's sexuality. By having caregivers define their values and interests regarding sexuality, they will be better prepared to communicate with each other and their child about intimate issues. Having the caregivers actively involved in the communication process increases awareness of personal values about sexuality. As values are defined and shared, a strong foundation will be formed on which to begin the educational process. The Defining Values Worksheet aids caregivers in determining the importance of addressing sexuality with their child and considering their goals and dreams for the child's future. Research shows that sexuality should occur in the home with caregivers serving as primary educators. By completing the Defining Values Worksheet, caregivers will be better suited to choose which topics must be addressed and which may be inappropriate at this time. The information the caregiver provides, in collaboration with the CSP and School-based Sexuality Checklist, will be essential for shaping the child's future sexuality goals.

## *Part III: Child Sexuality Profile*

The Child Sexuality Profile (CSP) is a client centered assessment tool designed to determine a child's current sexuality knowledge and his or her values and perceived competency in sexuality. The CSP focuses on the child's current knowledge and

perception of competence in the areas of anatomy, personal hygiene, pubertal changes, personal boundaries, and sexual expression. The CSP helps the therapist to learn what type of sexuality goals the child wants and what is most important to him or her. The CSP may be used by occupational therapists in collaboration with the child's primary caregiver(s) and educators who are concerned with understanding the young client's self-perceptions, values, and knowledge of sexuality.

The CSP consists of a competency rating scale and a values rating scale, each including a series of statements pertaining to everyday sexuality occupations. Knowledge flashcards may be used to determine the child's current knowledge in various areas of sexuality and to prompt additional conversation on sexuality topics. Pictorial illustrations are included on each flashcard to facilitate understanding among lower functioning clients with cognitive delays. The CSP's self-rating design allows the child to determine his or her perception regarding sexual values, personal causation and performance capacity using familiar visual aids and simple vocabulary. The CSP provides youth with the opportunity to express their views about sexuality including values and future relationship goals such as getting married and having children. This assessment is designed to be used collaboratively with the child and parents and educators, indicating the need for open communication and collaboration between each contributor. Most children, with the appropriate supports, can complete the CSP with clinical interpretation of performance and assessment results.

#### *Part IV: School-based Sexuality Checklist*

The School-based Sexuality Checklist allows the child's educators to provide input into the child's sexual behaviors in the academic setting. Since an educator typically has experience working with the child in multiple physical and social situations, the School-based Sexuality Checklist provides valuable input into the child's current behavioral patterns and knowledge that may otherwise go undetected. The assessment aims to determine a student's ability to make choices, fulfill their current roles and routines, and function within the classroom environment. The five sexual areas included are anatomy, pubertal changes, personal hygiene, personal boundaries, and sexual expression.



# Administering the YSI

The following section provides directions for administering each of the YSI sub-tests:

## *Part II: Caregiver Defining Values Worksheet*

- Determine appropriateness of caregiver participation in YSI
- Determine caregiver motivation in completing Defining Values Worksheet
- Explain purpose of Defining Values Worksheet in relation to YSI assessment
- Provide worksheet to primary caregivers of the child who plan to be actively involved in providing sexuality education
- Instruct each participant to take their time while thoroughly completing worksheet independently (worksheet may be taken out of clinic to complete)
- Instruct caregivers to utilize Defining Value Worksheet as a means to communicate with each other towards mutual values and understanding
- Discuss collaborated value conclusions with caregivers

Time Requirements: The Caregiver Defining Values Worksheet can take anywhere between 30-45 minutes to complete. Discussion with other primary caregivers to determine mutual values may take various amounts of time depending on the variability between worksheets.

## *Part III: Child Sexuality Profile*

### Preparing for the CSP

- Determine the appropriateness of administering the YSI and if special considerations are needed to complete the CSP sub-test.
- Create an environment that is conducive to administering the CSP. The environment should be private, quiet and free from distractions.
- Explain the purpose and process of the CSP to the child.
- Prior to testing, cut out the sorting cards and flashcards, and place them in order in three piles - Competency Rating Scale Cards, Values Rating Scale Cards, and Knowledge Flashcards.
- Have the Knowledge Flashcards Supplemental Questions easily accessible throughout the assessment.
- Have a blank copy of the CSP Summary Form with you to record child responses.
- If a child is lower functioning, the therapist in collaboration with the child's primary caregiver is encouraged to collect supplemental pictures and items that may promote understanding of the card and flashcard item. Materials are not be used to prompt specific responses, but rather to promote understanding of the question so the child is able to express his/her desired response.
- Note: It may be helpful to number sorting cards according to the CSP Summary Form. Laminating the sorting cards and flashcards is recommended for preservation.

#### Administering the CSP: Self-rating Scales

- Place the Rating Scale in front of the child. Complete the Competency Rating Scale first, followed by the Values Rating Scale. Directions for administering both scales are as follows.
- Hand the child the first card item and read the card aloud for the child. Remember to speak slow and clear. If the child does not understand the therapist or someone familiar with the child, such as a parent or a paraprofessional, may explain the card using alternative terminology. If the child still does not comprehend the card item, move to the next card and note the response on the summary sheet.
- Have the child determine if they are good at doing this, if they do this okay, or if they are bad at doing this.
- Have the child indicate their response by placing the card on the rating scale item.
- Record the child's response on the CSP Summary Form.
- Remove the card item from the Rating Scale and select the next card.
- Continue this process until all cards have been rated. Follow with Values Rating Scale.
- When the rating scales are completed, collect the cards and place them back in order according to the CSP Summary Form.

#### Administering the CSP: Knowledge Flashcards

- Place the first card (Card A) in front of the child.
- Provide a brief introduction to the card, indicated on the Knowledge Flashcards Supplemental Question sheet.
- Ask the child the supplemental questions. Remember to speak slow and clear. Don't rush the child. They may need additional time to process the information and respond. If the child does not understand the therapist or someone familiar with the child, such as a parent or a paraprofessional, may explain the flashcard using alternative terminology. If the child still does not comprehend the flashcard item, move to the next card and note the response on the summary sheet.
- Record the child's response on the CSP Summary Form.
- Remove the flashcard item and provide the next flashcard.
- Continue this process until all flashcards and responses have been completed.
- Note: If additional questions arise the therapist may prompt discussion with child. Record questions and responses on the CSP Summary Form.

Time Requirements: The CSP typically takes between 45-90 minutes depending on the child's cognitive abilities. The CSP sub-tests may be administered in separate sections if deemed appropriate by the therapist; however, all three parts should be completed within a two week period to encourage consistency of results. Short attention span and poor concentration are example characteristics in which this would be appropriate.



### *Part IV: School-based Sexuality Checklist*

- Determine appropriateness of teacher participation in YSI
- Explain purpose of School-based Sexuality Checklist in relation to YSI assessment to educator
- Provide checklist to primary educator who has the most experience working with the child and regular exposure to child throughout the school day.
- Instruct educator to complete the School-based Sexuality Checklist by reviewing the checklist items and marking the box according to the child's behavior.
- The teacher is to utilize information gained from the six month period prior to the assessment date.
- The educator is to use the following criteria to base the scoring:

**"Very Often"** indicates performance >75% of the time.

**"Occasionally"** indicates performance approximately 50% of the time.

**"Rarely"** indicated performance <25% of the time.

**"Never"** indicates the performance does not occur.

- If questions on the assessment are not applicable to the child or are unknown by the educator, the teacher is simply to indicate that on the checklist form.
- Instruct educator to utilize comment sections and additional concerns space to elaborate on checklist items to ensure greater understanding of child's sexuality in the academic setting.
- Review School-based Sexuality Checklist and ask for additional information from educator as needed.
- Note: The educator may be provided with the supplemental purpose and instruction sheet if necessary.

Time Requirements: The School-based Sexuality Checklist typically takes 45-60 minutes to complete depending on the educator's familiarity with the child being assessed. If necessary, the educator may complete the checklist for multiple school days to monitor specific behaviors relative to checklist items.

### *Part V: Integration*

Using the information gained through the Caregiver Defining Values Worksheet, Child Sexuality Profile Summary, and School-based Sexuality Checklist, the therapist is to integrate key components from each source to determine primary areas of concern and future sexuality outcomes. Cross referencing of the five sexuality areas of anatomy, hygiene, pubertal changes, personal boundaries and sexual expression will assist the therapist in determining the key areas of concern and goals identified by each participant. The process of developing sexuality goals should be a collaborative process in which the therapist does not dictate the conversation but rather facilitate discussion by each participant until a common conclusion is made. The Integration Worksheet may be used as a communication tool to promote mutual understanding and collaboration towards goals among all YSI participants, as well as ensure consistency in sexuality education across all contexts. The therapist shall instruct each participant in

the MLE theory and the child's primary mediators should be determined. It is important to remember that more than one mediator may be appropriate. For example, a parent and educator may both be mediators as long as the approach to sexuality is consistent by both.

Specific strategies for both the school and home contexts are recommended for each participant. This will allow each participant to recall role specific, child-friendly methods to address each area of concern in the various contexts. A copy of the integration data and additional resources should be provided to each participant to reference when necessary. These may be duplicated from the Parent Resource Packet.

The child's progress made towards outcomes may be reviewed if appropriate. In a situation where the therapist is working with the child for an extended period of time, reviewing outcome measures will determine progress gained and expose additional areas of concern. All participants may meet at the review sessions to share cognitive and behavioral changes observed. New outcomes may be developed as goals are met and additional areas of concern arise. The Revision Worksheet may be used to track changes to the child's sex education program. Duplicates of this worksheet may be made by the therapist to record revisions to each area of concern.

# Models Guiding Development

## *Model of Human Occupation*

The YSI is based on the Model of Human Occupation (MOHO) and its components. In MOHO, humans are conceptualized as being made up of three interrelated components: Volition, Habituation, and Performance Capacity (Kielhofner, 2008). MOHO is not designed for a specific type of impairment, but rather is applicable to any person experiencing problems in occupational life and across the lifespan.

Volition consists of the individual's values (what is important and meaningful), interests (what is enjoyable and satisfying), and personal causation (sense of competence and effectiveness). Volition refers to the motivation for occupation. It is defined as a pattern of thoughts and feelings that predisposes and enables people to anticipate, choose, experience, and interpret behavior.

The YSI addresses volition through the Caregiver Defining Values Worksheet. The worksheet assists caregivers in determining what he or she feels is meaningful for their child's sexuality and their sense of competence in addressing the areas of sexuality through education. The YSI addresses the child's volition through the CSP portion of the assessment by acknowledging what sexuality areas are prioritized by the child and their relationship desires and needs.

Habituation refers to the processes that maintain a pattern in everyday life. It consists of habits and roles that ensure regularity and predictability to occupational behavior. An individual's roles provide both identity and expectations for behavior. Habits form from repeated behavior within the environment and specific contexts.

The YSI addresses habituation by considering the family's habits, each caregiver's educational role, and the role that culture plays in a child's perception of his or her own sexuality. A child's habits and routines in the academic setting are also considered as the teacher completes and shares the School-based Sexuality Checklist.

Performance capacity is the individual's ability to perform tasks depending on objective and subjective components. Objective components of performance capacity include physical aspects (i.e. musculoskeletal, neurological, cardiopulmonary, and other bodily systems) and psychological aspects (i.e. memory, perception, and cognition). Subjective components incorporate experience as a central factor in how individuals perform. The fundamental assumption of MOHO is that to learn any performance an individual must know how it feels prior to mastery.

The YSI analyzes the child's performance capacity by looking at the child's sexuality performance through the caregivers', the teacher's and the child's perceptions. Specific performance areas included are anatomy, personal hygiene, pubertal changes, personal boundaries, and sexual expression. The child's current sexual knowledge and cognitive abilities are addressed during the CSP sub-test.

MOHO recognizes the impact of environment on occupational performance. There are both physical and social environments. The physical environment consists of the objects and space that an individual interacts with during occupations. The social environment includes social groups and supports that surround the individual. The physical and social environment can provide supports and resources for participation, or may hinder the individual's performance in meaningful and purposeful tasks.

Both the home and academic environments are incorporated into the YSI assessment as an individual's occupational performance regarding sexuality may vary according to contextual factors.

For more detailed information, clinicians using the YSI should refer to the following resources that explain MOHO-based clinical reasoning processes and application:

Kielhofner, G. (2008). *Model of human occupation: Theory and application* (4<sup>th</sup> ed.). Baltimore, MD: Lippincott, Williams, and Wilkins.

The Model of Human Occupation website at:  
<http://www.moho.uic.edu>.

### *Mediated Learning Experience Theory*

In the Mediated Learning Experience (MLE) Theory a child's perception of the world and processing of information is facilitated by a mediator, such as a parent or caregiver. The MLE Theory posits that there are certain functions a child can master only through the mediation by an adult or a competent peer. The MLE is based on the assumption that the major factor causing cognitive differences among people is the presence of a mediator, indicating that an involved, knowledgeable parent can promote greater functioning in individuals with intellectual and developmental disabilities (Katz, 2005).

The more often and the earlier the individual is subjected to mediation the better the outcome. Likewise, the less mediation the developing individual is offered, the lower his or her capacity will be affected by direct exposure to environmental stimuli. The mediator or parent, guided by his or her intentions, culture, and personal values, selects and organizes the world the child is exposed to and how he or she interprets the stimuli presented (Katz, 2005). Through this mediation or filtering the child's cognitive functions and behavior patterns are affected, indicating the ability of parents to promote or inhibit a child's sexuality.

The basic assumptions of the MLE Theory were considered in the development of the YSI communication tool. Both the parent and educator may serve as mediators to the information a child is exposed to and how the information is processed. Therefore, both parents and educators need to have a uniform approach to the child's sex education, a task only feasible with adequate communication and mutual understanding and goal setting.

For more detailed information, clinicians using the YSI should refer to the following resources that explain MLE theory-based clinical reasoning processes and application:

Katz, N. (2005). *Cognition and Occupation Across the Life Span*. American Occupational Therapy Association: Bethesda, MD.

## Background and History of YSI

The YSI was developed based on the Child Occupational Self Assessment (COSA) to meet a much needed demand for a tool to determine sexuality values and performance capacity in adolescents with developmental and intellectual disabilities.

A COSA is a modification of the adult version of the Occupational Self Assessment (OSA) and the "Children's Self Assessment of Occupational Functioning" developed in 1990.

A series of studies have been conducted to determine psychometric properties of the COSA; however, the applicability of these studies to the YSI is questionable. It is recommended that the studies specifically aimed at determining psychometric properties of the YSI be conducted to ensure reliability and validity of assessment results.

## II: Caregiver Sexuality Packet

- Introduction
- Defining Values Worksheet
- General Educational Guidelines
- Additional Resources

# Caregiver Sexuality Packet

# Introduction

Sexuality is a basic human right, given to everyone despite his/her abilities. It is a key part of how people see themselves as well as the world around them. How people develop sexually depends upon the opportunities that are given to them to make decisions and to experience new things. All people are interested in expressing themselves sexually regardless of their developmental abilities. Research has shown that people with intellectual and developmental disabilities have the same sexual desires and dreams as normally developing peers.

Providing quality sex education for your child or adolescent with developmental and/or intellectual delays has many benefits. They may be able to protect themselves from abuse, unplanned pregnancy, and sexually transmitted diseases. Self-confidence may be gained as they realize their sexual feelings and desires are normal. Through sex education, adolescents can learn social skills that will help them to recognize and respond to situations. Education can prepare children to protect their own body and report sexual abuse to trusted adults. Sex education will help your child establish and maintain healthy and satisfying relationships.

Approaching sexuality with your child can be a frightening task. You may fear that discussing sex with your child will increase your child's sexual behaviors, but lack of education may create a greater risk. When a person is unable to develop themselves sexually, additional problems such as anxiety and depression, as well as impaired self-esteem may occur.

Children with developmental and intellectual delays may not learn all they need to know about sexuality from friends, books or watching others. Resources that address sexual issues with disabled individuals may be difficult to find and use. In addition, educational materials created for children without developmental delays are not helpful for those with cognitive problems. This leaves parents to address this important topic with their child. Child doctors and teachers encourage parents to be the primary teachers of sex education and to consider their family values, cultural traditions, and religious beliefs. However, many times parents may not know the amount of sexual knowledge that their child currently has. Resources are available to assist in choosing the most effective words to use and ways to teach sexuality to their child; however, without a basic understanding of the child's current knowledge a caregiver/parent may not know where to begin.

The information gained through the Youth Sexuality Index (YSI) will help you in successfully determining your child's current sexual knowledge and the values of everyone involved. Each part of the YSI will provide information to set sexuality goals for your child. Each participant will communicate with each other to identify common concerns and goals. The Defining Values Worksheet, Child Sexuality Profile (CSP), School-based Sexuality Checklist, and the following additional resources will help you in this challenging, yet rewarding task of educating your child about sexuality.

**We hope you find this product helpful for both you  
and your child!**



## Introduction: Defining Values Worksheet

The following Defining Values Worksheet is to be filled out by all primary caregivers of the child who plan to be involved in providing sex education to the child. Research has shown that parents should be the primary sex educators for their child with developmental delays and should use values, cultural traditions, and religious beliefs. By defining your own values regarding sexuality, you will be more ready to communicate with other caregivers and your child about sexuality issues. Unclear understanding of values may lead to problems, such as avoiding the topic of sexuality, experiencing difficulty setting goals, and making choices that separate your child from others. As values are defined and shared, a strong base will be formed on which to begin the educational process. By determining the importance of addressing sexuality with your child and considering your goals and dreams for their future, you will be able to choose which topics should be addressed.

Please take your time while filling out the Defining Values Worksheet and use the worksheet as a reference while sharing your values with other primary caregivers. The therapist will be interested in discussing your worksheet information with you. The information you provide, in collaboration with the CSP and School-based Sexuality Checklist, will be necessary to make your child's future sexuality goals.

# Defining your Values: Sexuality & your Child

## Anatomy:

Is it important that your child has knowledge of sexual anatomy? \_\_\_\_\_  
Why or why not? \_\_\_\_\_

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What is your child's current knowledge of anatomy? What terms do you and your child use when discussing body parts? \_\_\_\_\_

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What is your comfort level in addressing this topic with your child? \_\_\_\_\_

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What past experiences have you had in addressing anatomy with your child and how did he/she respond? \_\_\_\_\_

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## Hygiene:

What goals do you have regarding your child's hygiene and personal care abilities? \_\_\_\_\_

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What is your child's current level of independence in performing hygiene tasks? In what areas does he/she need assistance? \_\_\_\_\_

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Does your child demonstrate awareness of personal appearance and cleanliness? \_\_\_\_\_  
Explain. \_\_\_\_\_

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What is your comfort level in addressing this topic with your child? \_\_\_\_\_

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What past experiences have you had in addressing hygiene with your child and how did he/she respond? \_\_\_\_\_

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Does your child have regular hygiene routines established and what do they consist of?

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### Pubertal Changes: (If applicable)

What are your primary areas of concern regarding your child's current or future pubertal changes? \_\_\_\_\_

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How is your child handling the physical and emotional changes that are occurring? (Examples: menstrual cycles, developing body parts, emotions, etc.). \_\_\_\_\_

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What is your comfort level in addressing this topic with your child? \_\_\_\_\_

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What past experiences have you had in addressing pubertal changes with your child and how did he/she respond? \_\_\_\_\_

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If your child is female, do you integrate menstrual cares into your child's daily routine? Explain. \_\_\_\_\_

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### Personal Boundaries:

How important is it that your child maintains his/her and others personal boundaries? \_\_\_\_\_

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Does your child demonstrate appropriate physical boundaries with others? \_\_\_\_\_  
Explain. \_\_\_\_\_

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Does your child discuss socially appropriate topics when conversing with others? \_\_\_\_\_  
Explain. \_\_\_\_\_

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What is your comfort level in addressing this topic with your child? \_\_\_\_\_

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What past experiences have you had in addressing personal boundaries with your child and how did he/she respond? \_\_\_\_\_

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## Sexual Expression:

How are sexual issues approached within your family? Is sexual expression demonstrated frequently? \_\_\_\_\_

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Is teaching your child about sex something that you value? \_\_\_\_\_

Why or why? \_\_\_\_\_

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How important is it for your child to have knowledge regarding sex and sexual expression? Why? \_\_\_\_\_

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What long term goals do you have for your child to express sexuality and experience intimacy in relationships? \_\_\_\_\_

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Does your child show interest in expressing him/herself sexually? \_\_\_\_\_

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What are the biggest concerns that you have about your child's sexuality? \_\_\_\_\_

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What forms of sexual expression would be appropriate for your child in his/her present routine? \_\_\_\_\_

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# General Educational Guidelines

The following are general guidelines that have been recommended in academic research and have found to be effective ways in which to educate children with developmental delays. These guidelines may be helpful to consider as you begin addressing sexuality with your child.

- Teach your child chronological age-appropriate information
- Discuss sexuality routinely and openly at a young age
- Teach sexuality and affection as being positive and pleasurable
- Help practice appropriate affection
- Use visual aids and simple words
- Always keep environment/context in mind
- Provide practice opportunities
- Encourage questions
- Be as concrete as possible
- Be consistent in your teaching
- Model privacy to your child
- Set rules related to touch as early as possible
- Respect your child's privacy and choices
- Teach your child the right to refuse
- Teach behaviors that conform to family and societal standards
- Use accurate language for body parts and bodily functions
- Teach child to label body parts and feelings accurately
- Ask permission before touching your child
- Describe what you are doing to your child during intimate cares
- Discuss/communicate why a touch occurred

# Additional Sexuality Resources for Parents

## Books

- **Just Because I Am: A Child's Book about Affirmation**—by L Murphy Payne; Free Spirit Publishing, 1994; available at [www.freespirit.com](http://www.freespirit.com)

This simply written book encourages your child to value his/her uniqueness and includes empowering messages about the body, feelings, boundaries, touch, and feeling safe. It also has a Leader's Guide of supplemental activities to evaluate what your child has learned regarding the topics stated above.

- **Face Your Feelings—Child's Work / Child's Play.** [www.childswork.com](http://www.childswork.com); 1-800-962-1141

This book and card deck set, for ages four and up, can help children to understand the importance of expressing and understanding their feelings. The book and card deck include 52 pictures of children, teens, and adults expressing 12 basic feelings.

- **What's the Big Secret: Talking about Sex with Girls and Boys**—by M Brown and L Krasny Brown, Ed.D; Little Brown Company, 2000

This easy-to-read story book for young children addresses how boys and girls are different and social rules about talking, looking, touching, and being touched.

- **What's Happening to My Body: A Book for Boys**—by Lynda and Area Madaras; Newmarket Press, 2000

This straightforward book discusses puberty and the male body. A workbook companion piece entitled, *My Body, My Self for Boys*, can be purchased separately and includes games, checklists, and quizzes to reinforce what boys have learned.

- **What's Happening to My Body: A Book for Girls**—by Lynda and Area Madaras; Newmarket Press, 2000

This straightforward book discusses puberty and the female body. A workbook companion piece entitled, *My Body, My Self for Girls*, can be purchased separately and includes games, checklists, and quizzes to reinforce what girls have learned.

- **Sexuality: Your Sons and Daughters with Intellectual Disabilities**—by K Schwier and D Hingsburger; Brookes Publishing, 2000

This book addresses sexual development issues from birth to adulthood. Parents, and their sons and daughters with developmental disabilities share stories that can be helpful for raising sexually healthy children. Many portions of the book speak specifically to people with Down syndrome and their parents.

## Product Links

**Marsh Media** – This website provides parents with illustration books and animated DVD's on various sexuality topics such as personal hygiene, anatomy, puberty, etc.  
<http://www.marshmedia.com>

**Teach A Bodies** – This website sells anatomically correct, instructional dolls to facilitate communication with children about sexuality. Products available include: anatomical dolls, life sized dolls, paper dolls, and booklets as well as accessories. Dolls come in various skin tones and can be customized by hair color, facial features, and style.  
<http://www.teach-a-bodies.com>

## Organization/Websites

**American Association on Mental Retardation (AAMR)**  
444 North Capitol Street, NW, Suite 846  
Washington, DC 20001-1512  
Phone: 202-387-1968  
Toll free: 1-800-424-3688  
<http://www.aamr.org>

**American Academy of Pediatrics**  
141 Northwest Point Blvd.  
Elk Grove Village, IL, 60007  
Phone: 847-434-4000  
<http://www.aap.org/>

**National Dissemination Center for Children with Disabilities**  
P.O. Box 1492  
Washington, DC 20013  
Toll free: 1-800-695-0285  
Phone: 202-884-8200  
<http://www.nichcy.org>

**National Information Center for Children and Youth with Disabilities –**  
P.O. Box 1492  
Washington, DC 20013  
(800) 695-0285  
[www.nichcy.org](http://www.nichcy.org)

**Sexuality Information and Education Council of the United States (SIECUS)**  
130 West 42nd Street, Suite 350  
New York, NY 10036-7802  
Phone: 212-819-9770

**The Arc: National Organization on Mental Retardation**  
1010 Wayne Avenue, Suite 650  
Silver Spring, MD 20910  
Phone: 301-565-384



### III: Child Sexuality Profile

- Competency Rating Scale and Cards
- Values Rating Scale and Cards
- Knowledge Flashcards
- Knowledge Flashcards Supplemental Questions
- CSP Summary Form

## Competency Rating Scale

**I am good  
at doing this.**



**I do  
this okay.**



**I am bad  
at doing this.**






## Competency Rating Scale Cards - 1

|                                 |                                |                            |
|---------------------------------|--------------------------------|----------------------------|
| Washing my body                 | Putting on clean clothes       | Washing my hands           |
| Brushing my teeth               | Using the toilet               | Shaving my face            |
| Changing my tampon/pad          | Asking to go to the bathroom   | Keeping my hands to myself |
| Doing things with my classmates | Asking for help when I need it | Making new friends         |
| Do things with my friends       | Following the rules at school  | Respecting the teacher     |

## Competency Rating Scale Cards - 2

|                     |                     |                            |
|---------------------|---------------------|----------------------------|
| Keeping secrets     | Talking to others   | Respecting others space    |
| Showing my feelings | Playing with others | Being private with my body |
| Being a boyfriend   | Being a girlfriend  | Loving others              |

## Values Rating Scale

|   |  |
|---|--|
| <p><b>I want to<br/>do this.</b></p>        |    |
| <p><b>I do not know<br/>about this.</b></p> |   |
| <p><b>I do not want<br/>to do this.</b></p> |  |

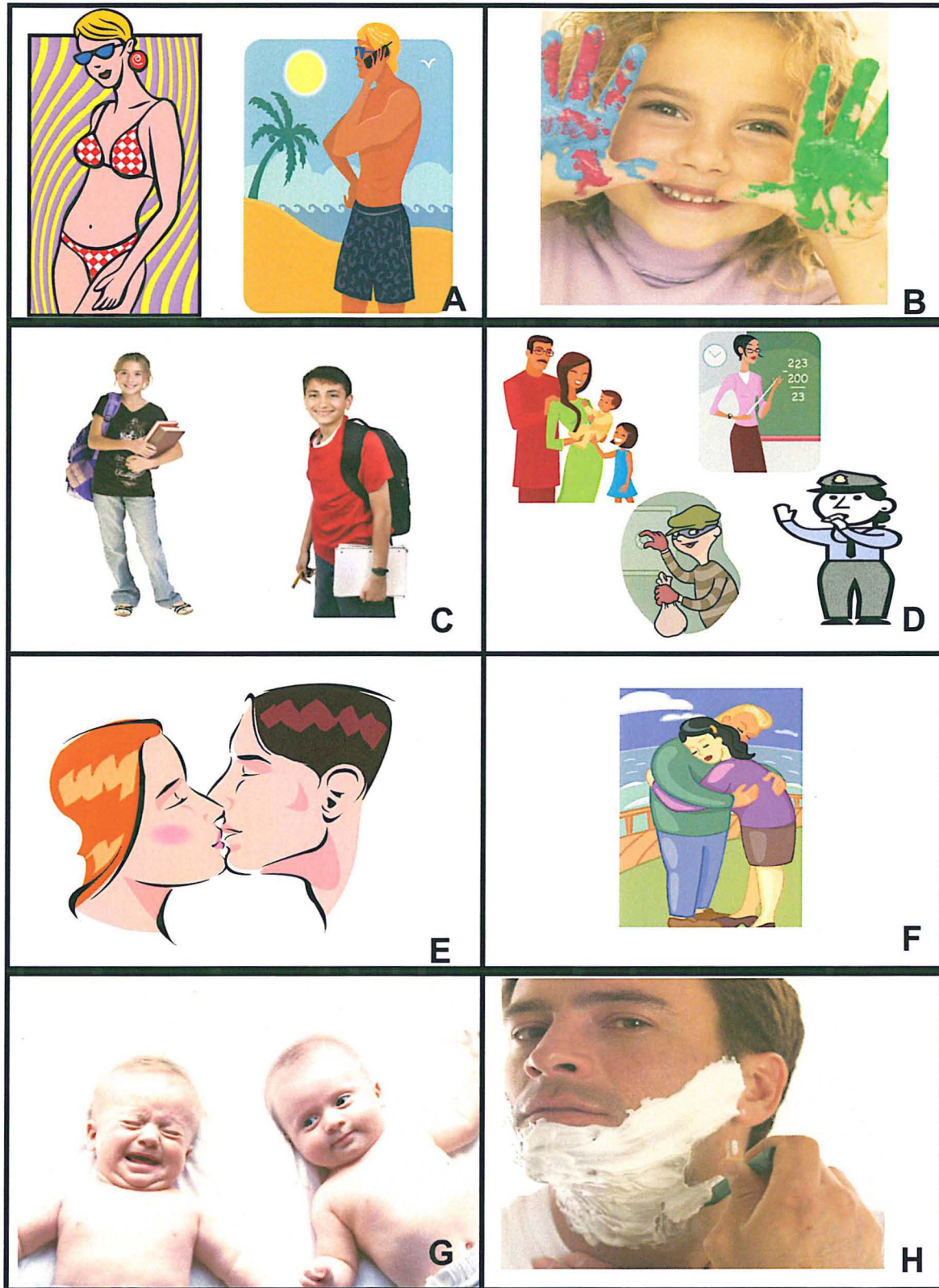
Note: Clipart obtained from Microsoft Office 2003.

## Values Rating Scale Cards - 1

|                             |                           |                      |
|-----------------------------|---------------------------|----------------------|
| Have a clean<br>body        | Smell<br>clean            | Look nice            |
| Use the toilet<br>by myself | Do things for<br>myself   | Go on dates          |
| Hug                         | Kiss                      | Get married          |
| Have a baby                 | Have a<br>boyfriend       | Have a<br>girlfriend |
| Have sex                    | Touch my<br>private parts | Protect my<br>body   |

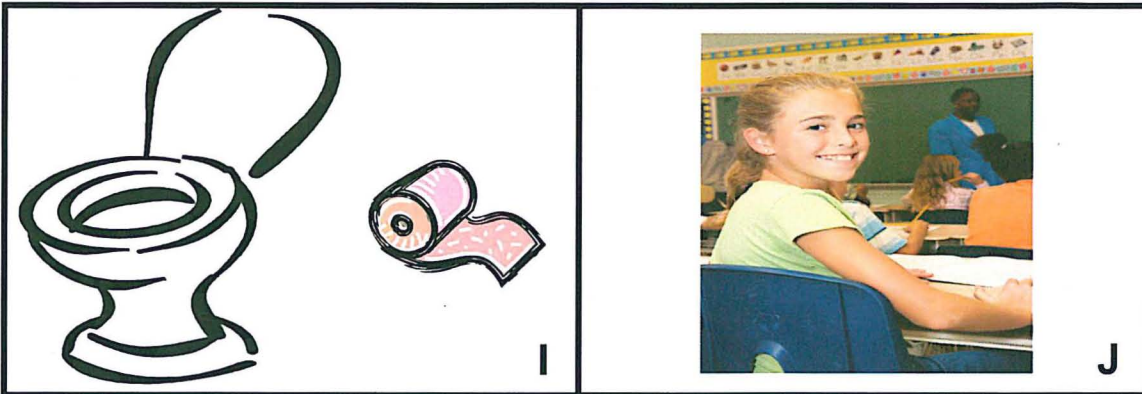


# Knowledge Flashcards - 1



Note: Clipart obtained from Microsoft Office 2003.

## Knowledge Flashcards - 2



Note: Clipart obtained from Microsoft Office 2003.

- Cut out flashcards prior to administering the CSP.
- Cards may be laminated for preservation.



# Flashcard Supplemental Questions

The following are additional questions the therapist may use with the flashcards to determine the child's current understanding and competency in sexuality knowledge. The five areas of sexuality including: anatomy, hygiene, pubertal changes, personal boundaries, and sexual expression are incorporated.

## Card A:

The therapist may provide an introduction to the card stating that the boy and girl are both wearing swimming suits and that swimming suits cover a person's private parts.

1. What body parts are covered by the girl's swimsuit?
2. What body parts are covered by the boy's swimming trunks?
3. What are your private parts called?
4. Why do you cover them when going to the pool or lake?

## Card B:

The therapist may provide an introduction to the card stating the little girl has paint on her hands.

1. Are her hands dirty or clean?
2. How do you know they are dirty?
3. What would you do if your hands had paint on them?
4. Where would you go to wash your hands?
5. What things would you need to wash your hands?

## Card C:

The therapist may provide an introduction to the card stating here are a boy and girl going to school. They look ready to get on the bus.

1. Do you think these kids are clean or dirty? How do you know this?
2. What do you think these kids did to get clean before going to school?
3. What do you do to make sure you are clean before going to school?
4. What do you need to wash when you are in the shower/bathtub?

## Card D:

The therapist may provide an introduction to the card stating that these are people that you may see during the day.

1. Which of these people would it be okay to hug/kiss? Why?
2. Which of these people would it not be okay to hug/kiss? Why?
3. Which of these people do you hug/kiss during the day?
4. Which of these people would you tell secrets to?
5. Is it safe to talk to strangers?
6. When is it okay to talk to strangers?

## Card E:

The therapist may provide an introduction saying here are a boy and a girl.

1. What are they doing?
2. Why are they kissing?
3. Do you kiss people?
4. Who do you kiss?

**Card F:**

The therapist may provide an introduction saying here are a boy and a girl.

1. What are they doing?
2. Why are they hugging?
3. Do you hug people?
4. Who do you hug?
5. Are there people that you should not hug?

**Card G:**

The therapist may provide an introduction saying here are two babies.

1. Do you remember when you were a baby?
2. Where were you at before you were born?
3. Where do babies come from?
4. Do you know how babies are made/created?
5. Do you want to be a mommy/daddy someday?

**Card H:**

The therapist may provide an introduction saying here is man getting ready in the morning. Boys and girls need to do different things to get ready.

1. What is this boy doing?
2. What is the white foam on his face called?
3. Do you shave your face? If no, why not?
4. When do you need to start shaving your face?
5. Do you shave your legs? If no, why not?
6. When do you need to start shaving your legs?

**Card I:**

The therapist may provide an introduction saying here is a picture of a toilet and some toilet paper.

1. Where is the toilet in your house?
2. When do you need to use the toilet?
3. Does somebody help you when you use the toilet?
4. How do you know when you are done wiping with the toilet paper?
5. What do you do after you are done on the toilet?

**Card J:**

The therapist may provide an introduction saying here is a picture of a girl sitting at her desk at school. Boys and girls are different and their bodies are different too.

1. How are they different?
2. Have you heard about periods before?
3. What happens when a girl is having her period?
4. What does she need to use for her period to stay clean?
5. Do you use pads/tampons when you have your period? Do you need help?

# CSP Summary Form

Name: \_\_\_\_\_

DOB: \_\_\_\_\_

Gender:      Male ☐      Female ☐

Assessment Date: \_\_\_\_\_

Therapist: \_\_\_\_\_

## Competency Rating Scale:

| Myself                          | I am good at doing this | I do this okay | I am bad at doing this | N/A |
|---------------------------------|-------------------------|----------------|------------------------|-----|
| Washing my body                 |                         |                |                        |     |
| Putting on clean clothes        |                         |                |                        |     |
| Washing my hands                |                         |                |                        |     |
| Brushing my teeth               |                         |                |                        |     |
| Using the toilet                |                         |                |                        |     |
| Shaving my face                 |                         |                |                        |     |
| Changing my tampon/pad          |                         |                |                        |     |
| Asking to go to the bathroom    |                         |                |                        |     |
| Keeping my hands to myself      |                         |                |                        |     |
| Doing things with my classmates |                         |                |                        |     |
| Asking for help when I need it  |                         |                |                        |     |
| Making new friends              |                         |                |                        |     |
| Doing things with my friends    |                         |                |                        |     |
| Following the rules at school   |                         |                |                        |     |
| Respecting the teacher          |                         |                |                        |     |
| Keeping secrets                 |                         |                |                        |     |
| Talking to others               |                         |                |                        |     |
| Respecting others space         |                         |                |                        |     |
| Showing my feelings             |                         |                |                        |     |
| Playing with others             |                         |                |                        |     |
| Being private with my body      |                         |                |                        |     |
| Being a boyfriend               |                         |                |                        |     |
| Being a girlfriend              |                         |                |                        |     |
| Loving others                   |                         |                |                        |     |

### Values Rating Scale:

| Myself                   | I want to do this | I do not know about this | I do not want to do this | N/A |
|--------------------------|-------------------|--------------------------|--------------------------|-----|
| Have a clean body        |                   |                          |                          |     |
| Smell clean              |                   |                          |                          |     |
| Look nice                |                   |                          |                          |     |
| Use the toilet by myself |                   |                          |                          |     |
| Do things for myself     |                   |                          |                          |     |
| Go on dates              |                   |                          |                          |     |
| Hug                      |                   |                          |                          |     |
| Kiss                     |                   |                          |                          |     |
| Get married              |                   |                          |                          |     |
| Have a baby              |                   |                          |                          |     |
| Have a boyfriend         |                   |                          |                          |     |
| Have a girlfriend        |                   |                          |                          |     |
| Have sex                 |                   |                          |                          |     |
| Touch my private parts   |                   |                          |                          |     |
| Protect my body          |                   |                          |                          |     |

### Knowledge Flashcards Responses:

#### Card A:

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_

#### Card B:

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_

**Card C:**

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_

**Card D:**

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_
6. \_\_\_\_\_

**Card E:**

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_

**Card F:**

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_

**Card G:**

1. \_\_\_\_\_
2. \_\_\_\_\_

3. \_\_\_\_\_

4. \_\_\_\_\_

5. \_\_\_\_\_

**Card H:**

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

4. \_\_\_\_\_

5. \_\_\_\_\_

6. \_\_\_\_\_

**Card I:**

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

4. \_\_\_\_\_

5. \_\_\_\_\_

**Card J:**

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

4. \_\_\_\_\_

5. \_\_\_\_\_

**Additional Comments:**

## IV: School-based Sexuality Checklist

- Introduction
- School-based Sexuality Checklist

# Introduction: School-based Sexuality Checklist

The School-based Sexuality Checklist allows the child's educator to provide input into the child's sexual behaviors in an academic setting. Since an educator typically has experience working with the child in multiple physical and social situations, the School-based Sexuality Checklist provides valuable input into the child's current behavioral patterns and knowledge that may otherwise go undetected. The assessment aims to determine a student's ability to make choices, their current roles and routines, and their ability to function within the classroom environment. The five sexual areas included are anatomy, pubertal changes, personal hygiene, personal boundaries, and sexual expression.

The School-based Sexuality Checklist should be completed by the child's primary educator who has the most experience with the child and has regular exposure to child throughout the school day. The checklist is to be completed from information gained in the 6 months prior to the assessment date. The School-based Sexuality Checklist typically takes 30-45 minutes to complete depending on the educator's familiarity with the child being assessed. If necessary, the educator may complete the checklist over multiple school days to monitor specific behaviors relative to checklist items.

To complete the School-based Sexuality Checklist review the checklist items and mark the box according to the child's behavior.

Use the following criteria to base your scoring:

**"Very Often"** indicates performance >75% of the time.

**"Occasionally"** indicates performance approximately 50% of the time.

**"Rarely"** indicated performance <25% of the time.

**"Never"** indicates the performance does not occur.

If questions on the assessment are not applicable to the child or are unknown by the educator, the teacher is simply to indicate that on the checklist form. The comment sections and additional concerns space is provided for the educator to elaborate on checklist items to ensure comprehensive understanding of child's sexuality in the academic setting.



## School-based Sexuality Checklist

Student Name: \_\_\_\_\_

Gender:    Male   ☐       Female   ☐

Date of Birth: \_\_\_\_\_

Occupational Therapist: \_\_\_\_\_

School Grade: \_\_\_\_\_

Name of School: \_\_\_\_\_

Assessment Date: \_\_\_\_\_

## School-based Sexuality Checklist

| Question:   | Very Often | Occasionally | Rarely | Never | Unknown/NA |
|---|------------|--------------|--------|-------|------------|
| Child uses consistent vocabulary to refer to private parts.<br><br>Comments:                                    |            |              |        |       |            |
| Child questions opposite gender's anatomy.<br><br>Comments:   |            |              |        |       |            |
| Child is observed discussing anatomy parts with peers.<br><br>Comments:   |            |              |        |       |            |
| Child requests to use restroom independently.   |            |              |        |       |            |
| Child washes hands after using restroom.  |            |              |        |       |            |
| Child completes toileting process independently<br>(i.e clothing management, cleansings, etc.)<br><br>Comments: |            |              |        |       |            |

| Question:  | Very Often | Occasionally | Rarely | Never | Unknown/NA |
|--|------------|--------------|--------|-------|------------|
| Child recognizes when face is dirty and washing is needed.                 |            |              |        |       |            |
| Child recognizes when hands are dirty and washing is needed.               |            |              |        |       |            |
| Child is free of bodily odors while attending class.                       |            |              |        |       |            |
| Child demonstrates awareness of personal appearance.<br>Comments:          |            |              |        |       |            |
| Child's pubertal changes are disruptive to classroom setting.<br>Comments: |            |              |        |       |            |
| Child is observed discussing pubertal changes with peers.<br>Comments:     |            |              |        |       |            |
| Female child demonstrates awareness of menstrual cycle.<br>Comments:       |            |              |        |       |            |

| Question:   | Very Often | Occasionally | Rarely | Never | Unknown/NA |
|---|------------|--------------|--------|-------|------------|
| Female child recognizes need to change feminine hygiene products.<br><br>Comments:                  |            |              |        |       |            |
| Female child seeks assistance with managing feminine hygiene products when needed.<br><br>Comments: |            |              |        |       |            |
| Male child maintains facial hair.   |            |              |        |       |            |
| Male child is discrete when experiencing erection.<br><br>Comments:                                 |            |              |        |       |            |
| Child demonstrates unnecessary touching while interacting with other students.<br><br>Comments:     |            |              |        |       |            |
| Child respects teacher's personal space.<br><br>Comments:   |            |              |        |       |            |

| Question:   | Very Often | Occasionally | Rarely | Never | Unknown/NA |
|---|------------|--------------|--------|-------|------------|
| Child has verbal outbursts while others are talking.<br><br>Comments: |            |              |        |       |            |
| Child asks for private information from others.<br><br>Comments:      |            |              |        |       |            |
| Child shares inappropriate information with others.<br><br>Comments:  |            |              |        |       |            |
| Child expresses feelings/emotions in the classroom.<br><br>Comments:  |            |              |        |       |            |
| Child engages in healthy friendships with peers.<br><br>Comments:     |            |              |        |       |            |
| Child demonstrates sexual interest in others.<br><br>Comments:        |            |              |        |       |            |

| Question:  | Very Often | Occasionally | Rarely | Never | Unknown/NA |
|--|------------|--------------|--------|-------|------------|
| Child has been observed masturbating while at school.<br>Comments:   |            |              |        |       |            |
| Child has discussed masturbation with teacher or peers.<br>Comments: |            |              |        |       |            |
| Child has been observed intimately touching peers.<br>Comments:      |            |              |        |       |            |
| Child has been observed kissing peers.<br>Comments:                  |            |              |        |       |            |
| Child has been observed hugging peers.<br>Comments:                  |            |              |        |       |            |

Additional Concerns:

## IV: Integration

- Integration
- Revision Worksheet

# Integration

Area of Concern #1: \_\_\_\_\_

\_\_\_\_\_

## Desired Outcomes – Home

1. \_\_\_\_\_

Caregiver Strategies:

2. \_\_\_\_\_

Caregiver Strategies:

## Desired Outcomes – School

1. \_\_\_\_\_

Educator Strategies:

2. \_\_\_\_\_

Educator Strategies:



Area of Concern #2: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

### Desired Outcomes – Home

1. \_\_\_\_\_

Caregiver Strategies:

2. \_\_\_\_\_

Caregiver Strategies:

### Desired Outcomes – School

1. \_\_\_\_\_

Educator Strategies:

2. \_\_\_\_\_

Educator Strategies:

Area of Concern #3: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

#### Desired Outcomes – Home

1. \_\_\_\_\_

Caregiver Strategies:

2. \_\_\_\_\_

Caregiver Strategies:

#### Desired Outcomes – School

1. \_\_\_\_\_

Educator Strategies:

2. \_\_\_\_\_

Educator Strategies:

Area of Concern #4: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Desired Outcomes – Home**

1. \_\_\_\_\_

**Caregiver Strategies:**

2. \_\_\_\_\_

**Caregiver Strategies:**

**Desired Outcomes – School**

1. \_\_\_\_\_

**Educator Strategies:**

2. \_\_\_\_\_

**Educator Strategies:**

Area of Concern #5: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

#### Desired Outcomes – Home

1. \_\_\_\_\_

Caregiver Strategies:

2. \_\_\_\_\_

Caregiver Strategies:

#### Desired Outcomes – School

1. \_\_\_\_\_

Educator Strategies:

2. \_\_\_\_\_

Educator Strategies:

# Revision Worksheet

Concern Revised: # \_\_\_\_\_

Date: \_\_\_\_\_

Outcome Met: \_\_\_\_\_

\_\_\_\_\_

New or Modified Goal: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Concern Revised: # \_\_\_\_\_

Date: \_\_\_\_\_

Outcome Met: \_\_\_\_\_

\_\_\_\_\_

New or Modified Goal: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Concern Revised: # \_\_\_\_\_

Date: \_\_\_\_\_

Outcome Met: \_\_\_\_\_

\_\_\_\_\_

New or Modified Goal: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Concern Revised: # \_\_\_\_\_

Date: \_\_\_\_\_

Outcome Met: \_\_\_\_\_

\_\_\_\_\_

New or Modified Goal: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

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